

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

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African American, Higher Education

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SECTION I: GENERAL IMMUNIZATIONS AND HEALTH CARE

Eight respondents participated in the group, 4 male and 4 female. When asked what they do to take care of themselves, this group focused on work, family responsibilities and interaction and some recreation.

I. Prevention

Respondents made little distinction between those diseases they identified for children or adults. In addition to childhood diseases, respondents cited chronic diseases, and infections.

- Chicken pox
- Pink eye
- Common colds
- Measles
- Ear infection
- Diabetes
- Tuberculosis
- Ringworm
- AIDS

II. Immunizations

A. *Reasons not to get vaccinated*

- Cost

And, if they're making \$45 a day, for me to take off to get you immunized, that's \$45.

- Fear

The thought of actually having the disease or whatever is pushed into your child's body.

- Low Priority

These are the workers that come in on season and they're like us, they're on time schedules and time frames and to them that is not really a priority.

Surviving is more priority to them probably than anything.

B. Reasons to get vaccinated

They push them in the school system. Unless the school actually pushes a lot of parents to the point where if you don't have the shot, immunized, they have to pull them out of school, they won't get it done.

Protecting the child.

Health of the child.

Keep him away from diseases.

Safety if there are other children in the household cause that stuff can run through.

It's best to expose the kid now than have him suffer later.

C. Ways parents are reminded of vaccine schedule

- The respondents in this group relied most heavily on the doctor or clinic to remind them of their immunization schedule. Though the fact that the doctor gives you a card was mentioned, most mentioned that there would be a reminder sent.

Some physicians do just like the dentist do, what they'll do is they'll send a reminder out. They'll address it [to the child] because they used to send mail to the parent and the parent reads it and it's supposed to be for the child.

- There was minimal record keeping. Parents were relying more on the memorized schedule than on a physical record. The record keeping process was described as follows:

I have a little yellow card that they gave me and when you go to the doctor, they fill it out, they fill in whatever the child had and the date and the card says when the next one is due.

- Respondents made the following suggestions for keeping an accurate record of immunizations:

A book with a card with the records with your insurance card --- on the back of it.

On the refrigerator I have a large memo pad and I just fill it in, birth date, baby shots, anniversary.

B. Methods of tracking

- Respondents are relying primarily on memory or a doctor's reminder. They have identified the pattern of immunizations based on the child's age and attempt to adhere to that.

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

- There was no prior awareness of the immunization registry. The initial reaction to the registry was favorable, with respondents characterizing the registry as a good or even excellent idea. Respondents liked the perceived convenience which addresses mobile and busy lifestyles.

I just switched doctors recently and I had to go all the way back to my original doctor, they couldn't just FAX something. Then they finally did FAX it after I complained a lot. It would be more convenient for parents that move around a lot.

Convenient, quick, easy. Plus sometimes in my mind, sometime you do forget.

- The idea of the registry raised issues related to access and the type of information the registry would store.

It sounds like a good idea, and you say only some people going to get access to it, but what kind of information are you going to have as far as child's information?

- How one obtains the information was another question which surfaced.

It says it's going to help you obtain a copy, are you going to have to go to a facility to get a copy?

- Cost was a concern.

Is it going to be financially accessible to the people that really need it?

- Most appealing aspects were accessibility, tracking procedure, knowing the information is available, records for school registration, all records in one place
- Areas of concern were access, type of information, misuse of information

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- Respondents had no knowledge of the immunization registry and found it difficult to focus on the information at hand. Rather, they attempted to identify other sensitive information which might be included in the registry.
- Questions relevant to immunizations included the importance of the lot number. Not all respondents saw the significance right away.

I think it's important for tracking.

If something's wrong with the vaccination your child received, they could tell you what company made it, --- stop that vaccine from being administered.

B. Reactions to including home address and phone numbers

That's fine. I have no problem with that.

C. Reactions to including parent or child social security number

- On an unaided basis, the issue of social security numbers was raised. In this context respondents thought that the form was lacking because there was no unique identifier.

I understand people are really cautious about Social Security numbers and stuff, but if they don't have Social Security numbers, some kid could have the same name. How will they know whose child this is? It's important and Social Security numbers are everywhere.

- Once the question was posed, respondents were mixed on their comfort level with the use of the social security number. The prevailing concern was with the record attached to the social security number being defamed.

The Social Security number will last a person a lifetime. Once you screw up a Social Security number, you can't leave the country and come back and get another.

- Respondents were unable to cite any relevant advantages to having the social security number other than the unique identifier cited above. There were disadvantages. These included the perceived link of parents' and children's information and the accessibility of that information to the public.

If I don't want my name on there or my wife's name, they got my child's Social Security, they pull that up, they pull me up as well. Who knows, if you put this here, Social Security and what not, who's to say you can't pull it up on the Internet?

D. Reactions to including health care members enrollment (WIC, Medicare numbers)

- The purpose of using a WIC or Medicaid number was questioned because of the somewhat temporary nature of the benefits, and number.

It may not be a permanent number? Kids are on WIC up until a certain age and when they get off you don't need that information.

III. Access

A. Who should have access

People in the medical field, the doctor's office

- Teacher, the school
- School board/school administration
- Local clinic
- Parents, immediate family members in case of emergency authorized by the mother
- Law enforcement
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Only doctors or the parents or emergency would have access to this information I think.

B. Who should not have access

- General public
- Unrelated medical practitioners, e.g. chiropractor
- Estranged/divorced parent

Because who knows maybe they go to the doctor's to get their records and try to steal your child

C. Reactions to ideas of linking registry by computer to other health information systems

- A key issue with linking was that respondents saw the possibility for infinite links, i.e., systems linking to other systems with links. Respondents were unclear on whether the impact of this would be positive or negative. The evolution of the use of the social security card was cited as an example of how

things start out with one purpose, and the purpose grows so that it no longer resembles its original purpose.

If you allow this information to be linked to this system to be linked to that system to be linked to this system, then eventually that system is going to be linked to the global tracking system up there which everybody is tied in up there and all that is going on out here.

The larger picture is that these systems connected can basically only help you or me.

IV. Consent and inclusion

Respondents tended to react to the options in terms of the benefits to the children and the right of choice of parents. Ultimately, most of the respondents chose explicit consent for themselves and their families. Applying a public health approach, some shifted to automatic .

A. Reactions to “opting out”

- Respondents understood the opting out concept. Generally, when respondents reacted favorably to this option, they looked at it from the perspective of the children and the need to protect them. When respondents looked at this option unfavorably, it seemed that their perspective was more personal and driven by their need to make their own choice. In addition there were those who looked at this option as a convenience.

I guess if you don't give them notice you don't want this, you're giving them consent to do it basically.

I think number 1 [opting out] is real good especially if you're a person that travels a lot and if you move from state to state. I think it's real good especially if you don't have that kind of time or accessibility. Time is the key issue, but then on opting out, you kind of take away something from the parent as far as allowing them the decision making they have over that kid.

It's almost like a fail safe net where if you do it fine, if you don't do it fine, there's still that safety net to catch the child.

It would be my decision if I decided I didn't want to do that. I just want my decision and my consent.

- Consent and the control over that decision was an important factor for some respondents. The following quote captures the level of emotion associated with having that consent was denied:

You're violated.

B. Reactions to “consent option”

- This group of respondents continued to express their dual perspective, that is, that the option is rated more or less favorably depending on how well children will fare at the end. This option was not rated as highly for the children and it was for adults wishing to exercise their right to choose.

It would be a wrong one for the kid.

And that [immunization] will have a great big hole in it as it has now.

Not everybody will respond.

There are some parents that don't do things they're supposed to. It doesn't matter how important it is, for whatever reasons, they put that aside.

There'll be so many kids out there like there are now with no assistance, no health care at all. The net is over.

I think the people who physically understand what health care means, whether they're able to afford it or not, will consent.

Everybody wants to feel like they're in control of their lives. Everybody wants to be in control of their own decisions.

C. Reactions to “automatic option”

- From one perspective, the initial reaction to this option was negative because this option was perceived to take away the rights of parents. Others looked at this as a way to protect children from the inaction of parents. In addition, respondents reacted favorably to the fact that the rules and outcome would be the same for everyone, not just those whose parents took action.

Automatic, just a totally inclusive system.

I know it sounds crazy, but it's the best thing going.

It's not about us, it's not about the parents ... It's about the children. So it's all inclusive.

I'm sure there are some people out there that want to do the best for their kid but sometimes they don't.

SECTION 3: ATTITUDES AND PERCEPTIONS OF REGISTRIES

I. Most important benefits of registries

- The respondents, several of whom were teachers in addition to being parents, focused almost entirely on the outcome for children. The key benefit as they saw it was protecting the children.

The good thing I see about it, there are so many children out there who are not immunized and you know I think basically what they want to do is keep track of it and get these kids immunized because they are coming up with all these diseases and they're trying to prevent diseases.

It's for the kids.

II. Greatest concern(s)/biggest risk (s)

- The key concern was ultimately what happens to the data and whether it might somehow be used against the child later in life. There was even the allusion to racial implications.

I don't want to give you my child's name that you can pull up his entire history when he's 18.

This information could very well become black list information by the mere fact once they know all about you, your health styles, a lot of people will not hire you if you have health problems. A lot of people will not insure you if you have health problems. And, I'm not paranoid, but then you can also use this in terms of census, in terms of well what does the culture have.

II. Influence of health care provider in decision to participate in a registry

- There was no consensus on whether the doctor's recommendation could influence the respondent's decision to participate in the immunization registry. The pediatrician might influence some.

I think I would have enough intuitive self awareness to know whether or not the doctor thought it was a good idea. I would know internally it's a great thing to do. Sometimes you just know the right direction to go.

III. Suggestions/comments to people who are responsible for how system works

- The final recommendations were consistent with themes which emerged throughout the groups. That is, respondent are concerned that it is inclusive, that access is controlled and that the information is input accurately and securely.

It's a good idea but it may not be for everyone. Will it be for the rich and poor?

Ensure beyond a reasonable doubt that the information put in is in fact used for the purpose intended and by whom or be expected to suffer the consequences.

They have to make sure they check on the background information on the person that's putting in all the information.